

INCLUSIVE RESEARCHERS COLUMN

No Research About Us Without Us

Suzie Jessup & The Inclusive Research Network

In one of our last articles we promised to share our thoughts about our code of research practice that we use as a standard to make sure that the voice of people with intellectual disability is heard.

The history of our code of practice:

In 2012 the Centre for Disability Studies held an inclusive research conference in the Sydney University Law School with Disability Rights Activist Susan Salthouse as a special guest speaker along with Sally French, also an activist and social model theorist from the United Kingdom.

Suzie Jessup is one of the founding members of the Inclusive Research Network. She has been involved in inclusive research since 2010. She remembers many international and interstate guests who came to the conference.

During this conference, the convening group wrote a code of practice about making research inclusive as a guide for the presenters. The CDS Inclusive Research Network has now worked on this code putting it into Easy English. You might want to think about whether your organization would like to adopt a code of practice for research like this too!

THE CDS CODE OF PRACTICE (Easy English Version)

- No research about us without us!
- The people with disability own the research
- We do research that matters to us
- We present together
- We are inclusive
- We try to use and produce accessible research materials
- We try to research in an accessible way
- We are ethical in our research
- We want to change the research agenda.

A code of practice doesn't always mean that you are perfect in these areas. It's a set of standards that you can measure against.

Suzie notes some of the big challenges faced by the CDS Inclusive Research Network. For example, different people have different support needs. So she noted that things aren't always immediately accessible but the group tries to think ahead and make written materials accessible, such as the use of large print for people with vision impairment. It is part of the CDS Code of Research Practice that members are there to support one another to understand what they would like to research and how.

It's also hard for research findings to always transfer to real life. Susie says that the research she is involved in is slowly but surely meeting this goal.

Susie commented, that "Each time we do a research project and report on our findings, we are making research more available to everyone."

She explained that being an inclusive researcher is about teaching other researchers with a long research history that people with disabilities have voices. But also here are some other things the group thought too.

Researching is about:

- Putting ourselves in someone else's situation to imagine what would it be like - how would this person feel?
- Another way of putting yourself in the person's shoes
- Drawing upon your own and other people's lived experience
- Co-researching, which means we need to support one another
- Sharing different experiences and skills, different ideas.

The rights of an inclusive researcher:

Suzie thought it was important that we also think about the rights of the researcher with disability.

Using a list created together with the CDS Inclusive Research Network, she thought this was a good way to say it.

As a researcher we:

- Have a voice
- Are listened to
- Feel part of the group
- Respect confidentiality
- Our research is about something important to us
- Have flexibility
- Have choice and control
- Everyone brings something to the table
- Need mutual respect
- Can bring passion and joy
- Can have fun!

If you would like to join the Inclusive Research Network, please contact the co-ordinator Dr Tanya Riches:

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Suzie says

"Our group meets once a month on a Thursday afternoon at the Centre for Disability Studies.

Would you like to come and join us?"